Thinking is the Best Way to Travel

Dignity and Respect

BUREAU OF FACILITY STANDARDS

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"Thinking is the Best Way to Travel" is a play written by Andrew Becker, using a Numeric Vocabulary List. For example, to communicate "is," with a code of 094, Mr. Becker would first move his hand to indicate '0.' Then Mr. Becker would raise his foot 9 times (with someone counting aloud to verify the correct number) and raise his foot again 4 times.

The play depicts a synopsis of Mr. Becker's life, as well as his first-hand experience of the way people with disabilities are, and have been, treated. While Mr. Becker's play applies to all of the ICF/ID Conditions of Participation, it has been included in the Governing Body module because it is ultimately the responsibility of the Governing Body to ensure that all individuals, regardless of their disabilities, are viewed and treated as people.

We (403) are (093) very (974) grateful to (393) Mr. Becker for (390) sharing his (709) perspective.

This play is an exceptional educational tool for any reader and reminds us of the need to treat each other with dignity and respect.

Appendix I

THINKING IS THE BEST WAY TO TRAVEL

A One Act Play by Andrew Thatcher Becker *This play is dedicated to Jean-Dominique Bauby.*

Scene: Lights up. Center stage recliner. Next to recliner a chair. You (398) see a person in the recliner. A person enters from left stage side, sits in empty chair (listens to monologue as person in recliner mime's it).

VOICE:

The Dignity o(Risk

What if you (398) never got to make a mistake?

What if you (398) never got to make a decision?

What if you (398) spent three hours everyday just waiting?

What if you (398) never knew adulthood?

What if you (398) never got a chance?..... Anonymous

(dim lights, maybe spotlight)

VOICE: This is my chance for dignity and I'm willing to risk it all. I'm like everybody else. I get bored. I get lonely. People see me using my wheelchair and notice that I don't speak in words and they assume that I am mentally impaired. We used to say mentally retarded, but that is no longer politically correct so now we say mentally impaired. But I am not! People assume... Don't assume.... I am not disabled, I have disabilities, there's a huge difference. I was born with sever cerebral palsy, quadriplegia, asthma, scoliosis, pelvic deformity, multiple contractures, GI distress, reflux, lumbrical spasms, and have had aspiration pneumonia. These are simply conditions I've learned to live with- they do not make me "disabled". Despite the many disabilities I endure, I have learned to adapt and communicate in a unique fashion. My sister: Melissa developed a knee tap code system for me. 1 have approximately 1000 3-digit codes. In my language, numbers equal words. This system allows me to live and learn just like everybody else.

My public education began in Lewiston, Idaho with kindergarten. My mother and her friend, Karen, drove me to the Child Development Center everyday. In the third grade, I continued my education in Genesee, Idaho, closer to home. I rode the school bus with everybody else just like any other kid. Although I was the only student at school with a wheelchair, my unique status didn't stop them from befriending me and providing the best care. When I was seventeen I started attending Moscow High School, twenty miles from home. During my high school days, I had wonderful and dedicated educational aides who enhanced my experience and taught me the most valuable lesson- that my disabilities didn't keep me from making great (689) lifelong friends. Reacting, writing, and arithmetic are not the only things we learn during our education. We never stop learning. We never stop teaching.

(lights brighten)

I've given communication presentations to Certified Nursing Assistant classes, Beauty School classes, second and third grade classes, and Washington State University classes about helpful adaptations for PWD's.

(lights change to yellow)

My presentation to a second grade class of nineteen was great (689) fun! They were full of energy and anxious to meet me. My aide introduced me and explained my code system. As I tapped out the codes, one student wrote the numbers on the board while the others looked it up in my codebook. By the fourth code I tapped out the whole class was counting out loud as I tapped. They shouted out "I know! I know!" (*Lights flash as voice says "I know I know"*) they looked up the meaning of each code. They liked me right away, Second graders are not so civilized that they are inhibited from asking questions. They know what "hurtful words" mean and did not want to say anything hurtful. But they weren't afraid to ask personal questions either. They all wanted to shake my hand, put my foot on my wheelchair footrest, and walk out to the van to see how the lift and "seatbelts" for my wheelchair worked. As we drove away there were 19 young smiling faces yelling, "Good bye Andrew, come and see us again." I'll always remember those kids!

(lights dim slightly)

The responses by the twenty Washington State University students were great (689) to read. I gained self-confidence upon reading them. I learned that my code system, which I take for granted, is really quite remarkable.

In summary I'll remember what they wrote about my presentation: enjoyed it....awesome job....wanted more time....very impressive, ...very beneficial....hands on look at PWDs......you showed us why we take this class. I raised the awareness of these students and their teachers, helping them develop a higher level of acceptance, respect, and friendship with PWDs.

(lights change to yellow)

Opportunities for raising awareness about PWDs are everywhere all the time. Language is another way to raise awareness. The developmental disability community places a great (689) deal of emphasis on language. There is an important (719) reason for this. Language has consequences. Some words have negative stigma attached to them. Those words lead to negative stereotypes and negative mental images. Thoughts are formed by words and we need to be forming positive thoughts about PWDs. Language affects our self-esteem.

The following terms are suggested to describe persons with a disability in a more dignified manner,

Instead of: disabled, handicapped, crippled

> Use: Person(s) with a disability (PWD)

Instead of: Crippled by, afflicted with, suffering from, victim of, deformed

> Use: Person who has... or, Person with...

Instead of: Lame

> Use: Person who is mobility impaired

Instead of: Confined, bound, restricted to or dependent on a wheelchair

> Use: Person who uses a wheelchair

Instead of: Deaf and dumb, deaf mute, hearing impaired

>- Use: Person who is Deaf, hard of hearing

Politically correct language can increase equal treatment, awareness, access and acceptance. Thoughts, images, attitudes, and ideas expressed in language can be politically correct or politically incorrect. Those ideas and attitudes follow the language and become acceptable or offensive. By carefully using accurate language you (398) will be a good role model for others. You (398) will be teaching others about disabilities.

Over the years, terms have come and gone. "Idiot", "imbecile", "Mongoloid", "retarded", and "abnormal" have a negative stigma attached to them. "Confined to a wheelchair", "suffering from CP", "poor", "oppressed", and "dependant" are also terms with negative stigma. These terms lead to negative stereotypes and negative mental images. As I have mentioned, do not stereotype a person using a wheelchair, and not speaking as a person who has mental retardation. Thoughts are formed from words. We need to pay attention to the words we use.

(lights change to white)

I cannot emphasize enough the importance of a PW'D's network of professionals for their specific and individual needs. I don't want habilitation technicians that are parental. I'm 37 years old. A hab tech that is like a brother or sister or mentor is best. If I have a hab tech that spends a lot of time with me over a period of nine or ten years, we can't help but become friends. Remember this person is my arms and legs. He/She drives my car for me. He/She counts my codes and tells the person on the other end of the phone what I'm tapping, so at this time he/she is even my voice. I've seen him/her graduate from the University and maybe I've attended his/her wedding. He/She's seen me on my good days and my bad days. I've seen his/her good and bad days too.

There are four principles to help provide a humane environment. They are: reasonable accommodations, normalization, protection from harm, and least restrictive alternative. What we call the people who assist us is not important (719). The qualities they bring to their work are extremely important (719). We might call them assistants, aides, habilitation technicians, mentors, companions, caregivers, caretakers, certified nursing assistant, or staff. They translate my codes and meet my needs; whether I am bathing, dressing, toileting, eating, or riding in my car in the country.

(lights change to blue)

It takes a certain amount of emotional maturity to be other-oriented. To be other-oriented most of an eight-hour shift in a group home or a twenty-four hour shift in a residential habilitation apartment can be challenging. Simple tasks such as meals take on a new meaning when a route other than my mouth must be used. Because I could aspirate fluids or food into my lungs I use enteral nutrition. I take my water, medication and formula through a feeding tube that is inserted

in my stomach. I am NPO (nils per os), which means nothing by mouth. This can cause dry mouth, dry lips and a sore throat. A small discomfort when you (398) cosider the alternative. Aspiration could cause death.

There are a lot of other issues related to NPO tube feeding and I can speak from first hand knowledge. There is the smell of food in the group home while meals are being prepared and the sight of food when I go (111) out with friends for conversation while they eat and the sounds of my friends chewing and slurping while they eat near me. Then there are the birthday cakes and ice cream. Everything is so food centered in our culture. Food is used to celebrate. Food is used for comfort. And food is abused. I choose not to dwell on it and not to use NPO as a reason to get depressed.

(lights chauge to redf)

Sometimes I feel (075) angry because I have CP. However, I try to make my condition useful by helping others understand more. Our families, our caregivers, our advocates, our friends and the general public can also benefit by understanding more. Most people don't really know how it feels unless someone with a disability explains. I am someone and I can explain. I am really just like you (398). I get to go (111) to Mariners games, the space needle, the ocean, and Seattle. My cousin Tim takes me for motorcycle rides. I have my own car for rides in the country and to Lake Coeur d'Alene for weekends all summer. I watch CNN and listen to Frank Sinatra. I love to fly. I like it when people shank my hand, look me in the eye, tell me their good news, and laugh with me. I want what everyone wants, I want to be happy (080) and treated like the adult I am. Sometimes I feel (075) bored or tired of the same old problems. I want to let you (398) know how great (689) it feels to see someone I know almost every two blocks when I'm in the community. I call this the "two block-test of friendship". It's true my disability has taken some things away from me like walking, talking and eating. But it can't take friends away from me.

Ironically, my friend CP has given me opportunities others don't have. I flew to Boise every month for a year to give my input to the Governors' Task Force on delivery of services to PWDs. I write letters to the editor about uneven, icy, snow covered sidewalks, streets, and curb cuts, and sidewalks made too narrow by signposts, planters and trees. I'm proud to discuss my needs and feelings. Many PWDs can't communicate. With my legs and my brain I can communicate. Even though CP has kept me from speaking words like most people, CP has not been able to take my "voice" away! I am using my "voice" to help other PWDs. This is important (719) work I do and valid contributions I can make to my community.

(liglzts chmtge to yellow)

There is a saying: "If God gives you (398) lemons make lemonade." I've made a lot of lemonade in my life. I didn't have a choice about having CP, but I do have a choice about my attitude, feelings, and how to live my life. I'm pretty happy (080) most of the time as you (398) can see by my million-dollar smile. So, please visit with me, look me in the eye and shake my hand.

Don't worry about hurting my feelings. It would hur worse if you (398) didn't visit.

Short pause: Frank Sinatra's "Old Blue Eyes" begins playing softly in the background

VOICE: If I can walk. I can dance..... If I can talk. I can sing..... If I can think, I can dream..... I'm free.

Music gets louder. The reader (who is also dressed like AB) joins AB and person in chair on stage. They swoop AB out of the recliner holding him under his arms. The three of them take a bow. Curtain is lowered.

Supervisor of Milestone will talk (066) to the audience long enough for AB to move to the entrance of the theatre and greet the audience as they leave.

(This performance takes 15-20 minutes)

Numeric Vocabulary List

000	pause	040	hat	080	happy
001	talk	041	mittens	081	sad
002	talk repeat	042	purse	082	sorry
003	clear	٠.2	1	083	tired
004	echo			084	hurt
005	master clear	043	body	085	sick
006	switch off/on	044	hair	086	pain
000	5111011 311, 311	045	head	087	angry
		046	face	088	afraid
007	yes	047	eye	089	upset
008	no	048	ear	090	embarrassed
009	okay	049	nose	091	hungry
010	hello	050	teeth		
011	bye	051	back		
012	please	052	arm	092	am
013	thank you	053	hand	093	are
013	thank you	054	finger	094	is
		- 055	leg	095	be
014	family	056	feet	096	been
014	grandfather	050	Toot	097	have
016	grandmother			— 098	was
017	brother	057	wear	098	will
017	sister	058	change	100	I'm using an
019	dad	059	understand	100	artificial voice
020	mom	060	think	101	need
020	friend	061		102	help
021	man	062	cry see	103	like
022	woman	063	hear	103	want
023	boy	064	smell	105	give
024	girl	065	smile	106	take
025	baby	066	talk	107	keep
020	policeman	067	look	107	open
	teacher	068	listen	109	close
028 029	therapist	069	move	110	come
029	tilerapist	070	run	111	go
		- 070 071	walk	112	went
030	clothes	071	swim	113	start
030	shirt	072		113	
030		073	play work	115	stop
030	pants	074	feel	116	try can
033	dress suit	073	icci	117	can't
				118	do
035	sock	076	fine	119	don't
036	shoe			119	
037	sweater	077	excited	120	buy
038	jacket	078	surprise love	121	cost
039	coat	079	1016	122	get

100	4	166	1	209	letter
123	got	166	hour	210	
124	bring	167	day		A
125	call	168	week	211	В
126	speak	169	year	212	C
127	break	170	yesterday	213	D
128	make	171	today	214	E
129	cook	172	tomorrow	215	F
130	eat	173	morning	216	G
131	ate	174	afternoon	217	Н
132	wash	175	night	218	I
133	wet	176	Monday	219	J
134	dry	177	Tuesday	220	K
135	wake	178	Wednesday	221	L
136	sleep	179	Thursday	222	M
137	show	180	Friday	223	N
138	watch	181	Saturday	224	0
139	fight	182	Sunday	225	P
140	turn	183	January	226	Q
		184	February	227	R
		185	March	228	S
141	read	186	April	229	T
142	write	187	May	230	U
143	add	188	June	231	V
144	subtract	189	July	232	W
145	learn	190	August	233	X
146	thought	191	September	234	Y
147	circle	192	October	235	Z
148	square	193	November		_
149	number	194	December		
147		195	fall	236	spell
	-	196	winter	237	word
150	0	197	spring	238	class
151	1	198	summer	239	school
152	2	199	vacation	240	art
153	3	1//	vacation	241	book
153	4			242	mistake
	5	200	The next word	243	music
155		200		244	
156	6 7	201	is spelled sun	244	paper
157				246	pen
158	8	202	rain	247	pencil
159	9	203	snow		picture
160	10	204	wind	248	problem
161	11	205	sky	249	question
162	12	206	cloud	250	answer
		207	smoke		
		208	fire		
163	time			251	how
164	second			252	what
165	minute			253	when

254	whore	299	drawer	344	fun
254	where which	300	bathroom	345	all
255		301		346	
256	who	302	cupboard	347	enough more
257	why	303	cup	348	
			glass	340	some
250	- blook	304 305	dish knife		
258	black	303 306	fork	349	dirt
259	blue	307		350	clean
260	brown	307	spoon	351	
261	green				good bad
262	orange	200	food	352 353	
263	purple	308	food		big small
264	red	309	meat	354 355	
265	white	310	egg	355 356	full
266	yellow	311	cheese	356	empty
		312	vegetable	357	young
2.5		313	fruit	358	old
267	animal	314	sandwich	359	new
268	cat	315	cake	360	cold
269	dog	316	ice cream	361	hot
270	game	317	candy	362	fast
271	doll	318	drink	363	slow
272	balloon	319	water	364	easy
273	ball	320	milk	365	hard
274	boat	321	coffee	366	first
275	bike	322	sugar	367	last
276	car	323	breakfast	368	left
277	cab	324	lunch	369	right
278	bus	325	dinner	370	wrong
279	comb	326	house	371	a
280	brush	327	apartment	372	an
281	toothpaste	328	store	373	and
282	toothbrush	329	church	374	at
283	soap	330	hospital	375	because
284	towel	331	company	376	but
285	bath	332	elevator	377	if
286	shave	333	park	378	not
287	clock	334	city	379	or
288	radio	335	country	380	the
289	TV	336	farm	381	again
290	telephone			382	now
291	computer			383	on
292	light	337	sex	384	off
293	machine	338	birthday	385	ill
294	chair	339	name	386	out
295	table	340	appointment	387	up
296	door	341	address	388	down
297	lock	342	pill	389	by
298	room	343	thing	390	for

391	from			480	about
392	of	435	Easter	481	above
393	to	436	New Year's Eve	482	ache
394	with	437	New Year's Day	483	across
395	I	438	Christmas Eve	484	act
396	my	439	Christmas Day	485	after
397	me	440	Valentine's Day	486	against
398	you	441	Martin Luther King	487	age
399	he		Jr. Day	488	air
400	I need help	442	Veterans' Day	489	airplane
401	she	443	Mother's Day	490	alone
402	it	444	Father's Day	491	alphabet
403	we	445	President's Day	492	another
404	they	446	Thanksgiving	493	any
405	that	447	Halloween	494	anything
406	there	448	Columbus Day	495	apple
407	someone	449	Superbowl Sunday	496	as
408	something	450	Fourth of July	497	ask
	C	451	Labor Day	498	aunt
		452	Memorial Day	499	away
409	I'm ready	453	April Fool's Day	500	awful
410	My name is	454	Saint Patrick's Day		
411	How are you?	455	Spring Break		
412	I'm fine	456	Happy Holidays	501	backward
413	lam	457	Ash Wednesday	502	bag
414	I have	458	Good Friday	503	bake
415	I want	459	Mardi Gras	504	banana
416	I'm going	460	Hanukkah	505	bank
417	I'd like	461	World Series	506	bam
418	Would you come	462	Olympics	507	base
	here?	463	Special Olympics	508	basement
419	I don't understand	464	World Cup	509	basic
420	Please leave me	465	football	510	basketball
	alone	466	baseball	511	bat
421	My feelings are hurt	467	soccer	512	bathe
422	con-	468	golf	513	beach
423	dis-	469	fishing	514	bed
424	un-	470	handball	515	bedroom
425	-ed	471	wrestling	516	beer
426	-en	472	horseback riding	517	before
427	-er	473	softball	518	began
428	-es	474	diving	519	begin
429	-et	475	racing	520	behind
430	-ez	476	bowling	521	being
431	-ful	477	volleyball	522	believe
432	-mg	478	swimming	523	bell
433	-less	479	tennis	524	belt
434	-ly			525	bent
				526	beside

					
527	best	574	choose	619	dollar
528	better	575	Christmas	620	done
529	between	576	clear	621	dot
530	bill	577	close	622	draw
531	bird	578	collar	623	drive
532	bite	579	collect	624	drop
533	blanket	580	college	625	dye
534	blind	581	color		
535	block	582	command		
536	blow	583	common	626	each
537	board	584	complete	627	early
538	boot	585	control	628	east
539	born	586	cool	629	eighteen
540	both	587	copy	630	either
541	bottle	588	corner	631	end
542	bottom	589	couch	632	enemy
543	bought	590	could	633	engine
544	box	370	could	634	enter
545	bread			635	erase
546	broke	591	count	636	error
		592	cousin	637	
547	broom				even
548	brought	593	cover	638	evening
549	bug	594	cow	639	ever
550	build	595	crack	640	every
551	burn	596	crayon	641	everyone
552	business	597	cream	642	everything
553	busy	598	credit	643	example
554	butter	599	cross	644	experience
555	button	600	curl		
		601	curtain		
		602	cut		
556	cafeteria	-		645	fact
557	calendar			646	factory
558	came	603	dark	647	fan
559	care	604	date	648	far
560	carry	605	dear	649	father
561	case	606	decide	650	fear
562	catch	607	deer	651	fell
563	caught	608	dentist	652	female
564	center	609	dessert	653	few
565	cents	610	did	654	fifteen
566	chalk	611	die	655	fifty
567	chance	612	different	656	fill
568	check	613	difficult	657	finish
569	chest	614	dime	658	fireman
570	chicken	615	dining room	659	fish
571	child	616	divide	660	fix
572	children	617	doctor	661	flag
573	chocolate	618	does	662	flat
513	Chocolate	010	does	002	1141

0	ar.	= 00		- 40	
663	floor	708	him	749	lightning
664	flour	709	his	750	line
665	flower	710	hit	751	lip
666	fly	711	hole	752	little
667	foot	712	home	753	live
668	forget	713	hope	754	long
669	forgot	714	hug	755	loose
670	forty	715	hurry	756	lost
671	forward			757	lot
672	found			758	loud
673	fourteen	716	lee	759	low
674	free	717	idea		
675	front	718	immediate		
676	furniture	719	important	760	mad
		720	inch	761	made
		721	in-law	762	magazine
677	garage	722	insect	763	mail
678	garbage	723	inside	764	many
679	garden	724	into	765	match
680	gas	725	interest	766	measure
681	gave	726	iron	767	medicine
682	glue	,_0	1.01	768	men
683	God			769	merry
684	gold	727	jet	770	middle
685	_	727	job	771	mile
686	gone	729	juice	772	million
687	government	730	· ·	773	mine
688	grade	730	Jump	774	miss
	grass	/31	just	775	
689	great			776	money
690	grew	722	Irant	770 777	month
691	ground	732	kept		moon
692	group	733	key	778	most
693	grow	734	kick	779 700	mother
694	guess	735	kind	780	mountain
695	gum	736	kitchen	781	mouth
		737	knee	782	movies
				783	much
696	had				
697	half	738	lake		
698	hall	739	land	784	nail
699	hammer	740	large	785	natural
700	has	741	late	786	necessary
701	heart	742	laugh	787	neck
702	heat	743	law	788	never
703	heavy	744	lead	789	next
704	her	745	leave	790	nickel
705	here	746	less	791	nineteen
706	high	747	let	792	ninety
707	hill	748	life	793	noise

794	noon	837	quite	882	side
795	north			883	sign
796	nurse			884	sink
		838	ran	885	sit
		839	ready	886	sixteen
797	ocean	840	real	887	sixty
798	o'clock	841	reason	888	size
799	office	842	record	889	skirt
800	only	843	remember	890	sleeve
801	other	844	rest	891	slept
802	over	845	restaurant	892	slide
803	own	846	ride	893	slip
		847	road	894	so
		848	roll	895	soft
804	page	849	roof	896	song
805	pail	850	round	897	soon
806	pan	851	rule	898	sore
807	part			899	sound
808	pass			900	soup
809	paste	852	said	901	sour
810	pay	853	sail	902	south
811	peace	854	salad	903	space
812	people	855	salt	904	special
813	person	856	same	905	speech
814	pet	857	sand	906	sport
815	piano	858	sat	907	stairs
816	pick	859	save	908	stamp
817	pin	860	saw	909	stand
818	place	861	say	910	star
819	plan	862	scissors	911	state
820	plane	863	score	912	state
821	pocket	864	season	913	step
822	point	865	seal	914	stocking
823	police	866	secret	915	stomach
824	pool	867	seem	916	stone
825	poor	868	seen	917	stove
826	-	869	sell	918	straight
827	pop post	870	send	919	strange
828	post	870 871	sent	920	street
829	•	872	set	920	strong
830	present	872 873		922	student
	pretty	873 874	seventeen		student
831	pull	874 875	seventy shake	923 924	<u> </u>
832	push				sure
833	put	876 877	shampoo	925	sweet
		877 	shop		
024		878	short	007	to:1
834	quarter	879	should	926	tail
835	quick	880	shower	927	tall
836	quiet	881	shut	928	taste

929	team	967	uncle
930	tear	968	under
931	tear	969	underwear
932	tell	970	until
933	test	971	upstairs
934	thank	972	us
935	them	973	use
936	then		
937	these		
938	third	974	very
939	thirteen	975	visit
940	thirty	976	voice
941	this	977	vote
942	those		
943	throw		
944	thumb	978	wait
945	thunder	979	wall
946	ticket	980	warm
947	tie	981	way
948	tight	982	weather
949	tissue	983	well
950	toe	984	were
951	together	985	west
952	told	986	wheel
953	tonight	987	whole
954	took	988	wide
955	tooth	989	win
956	top	990	window
957	touch	991	wish
958	toy	992	women
959	train	993	wood
960	tree	994	wore
961	triangle	995	world
962	trouble	996	wrote
963	truck		
964	tub		
965	turkey	997	yard
966	twenty	998	your
	-		

Personal codes

Zero-right hand held up

